

## **PARKINSON'S DISEASE REGISTRY ACT**

### **81-697**

#### **Act, how cited.**

Sections 81-697 to 81-6,110 shall be known and may be cited as the Parkinson's Disease Registry Act.

#### **Source:**

Laws 2001, LB 152, § 5.

### **81-698**

#### **Purpose of registry.**

The purpose of the Parkinson's Disease Registry is to provide a central data bank of accurate, historical and current information for research purposes. The Parkinson's Disease Registry Act will provide for screening and collecting patient and family data that may be useful in detecting the incidence of and possible risk factors concerning Parkinson's disease and related movement disorders. The act will also aid in planning for health care requirements and education needs.

#### **Source:**

Laws 2001, LB 152, § 6.

### **81-699**

#### **Terms, defined.**

For purposes of the Parkinson's Disease Registry Act:

- (1) Approved researcher means an individual or entity who is approved by the department in accordance with section 81-666 to obtain access to data contained in the Parkinson's Disease Registry to assist in scientific or medical research for the prevention, cure, or control of Parkinson's disease;
- (2) Department means the Department of Health and Human Services Regulation and Licensure;
- (3) Parkinson's disease means a chronic, progressive disorder in which there is a lack of the chemical dopamine in the brain as a direct result of the destruction of the dopamine-producing cells in the portion of the brain called the substantia nigra. Clinical features of the disease include tremor at rest, slow movements, rigidity, and unsteady or shuffling gait and may be indicated by improvement after using medications used for Parkinson's disease; and
- (4) Related movement disorder means a disorder that resembles Parkinson's disease in some way, such as another kind of tremor.

#### **Source:**

Laws 2001, LB 152, § 7.

### **81-6,100**

#### **Parkinson's Disease Registry; contents.**

The department shall establish and maintain the Parkinson's Disease Registry. The registry shall consist of a compilation of the reports of cases of Parkinson's disease and related movement disorders occurring among residents of this state which are with the department. The registry shall include information the department deems necessary and appropriate for the statistical identification and planning for treatment and education of health care providers and persons diagnosed with Parkinson's disease and related movement disorders.

#### **Source:**

Laws 2001, LB 152, § 8.

**81-6,101****Department; duties.**

The department shall:

- (1) Adopt and promulgate rules and regulations, including a uniform system of classification of Parkinson's disease which is consistent with medically and clinically accepted standards and definitions for use in reporting by medical personnel treating the disease;
- (2) Execute any contracts that the department deems necessary to carry out the Parkinson's Disease Registry Act;
- (3) Receive and record the data obtained from reports filed under sections 81-6,102 and 81-6,103;
- (4) Compile and publish a statistical report annually or at reasonable intervals containing information obtained from patient data to provide accessible information useful to medical personnel, approved researchers, and the public; and
- (5) Comply with all necessary requirements to obtain funds or grants.

**Source:**

Laws 2001, LB 152, § 9.

**81-6,102****Diagnosis; report; contents.**

- (1) If a resident of this state is diagnosed with Parkinson's disease or a related movement disorder within this state in the office of a physician licensed under the Uniform Licensing Law, the physician shall file a report of the diagnosis and pertinent information with the department within sixty days after the diagnosis.
- (2) An individual resident of this state who has been diagnosed with Parkinson's disease or a related movement disorder by a licensed physician may file a report with the department providing relevant information. The department shall provide for validation of individual reports.
- (3) A report filed under this section shall contain the following information about the person diagnosed with Parkinson's disease or a related movement disorder:
  - (a) Name;
  - (b) Social security number;
  - (c) Date of birth;
  - (d) Gender;
  - (e) Address at time of diagnosis;
  - (f) Current address;
  - (g) Date of diagnosis;
  - (h) Physician;
  - (i) Identification of reporting source; and
  - (j) Any additional information the department demonstrates is reasonable to implement the Parkinson's Disease Registry Act.

**Source:**

Laws 2001, LB 152, § 10.

**Cross Reference:**

**Uniform Licensing Law**, see section 71-101.

**81-6,103****Pharmacist; report; department; duty.**

The pharmacist in charge of each pharmacy located within the state or doing business in the state shall file a semiannual report with the department listing persons to whom the pharmacist has dispensed drugs on the list of drugs required to be reported under this section for Parkinson's disease. The report shall include the name, address, and social security number of the person for whom the drugs were prescribed and the name and address of the prescribing physician. The department shall issue a list of drugs used for the treatment of Parkinson's

disease to be reported under this section, shall review and revise the list annually, and shall distribute the list to each pharmacy located within the state or doing business in the state.

**Source:**

Laws 2001, LB 152, § 11.

**81-6,104**

**Release of data; other sections applicable.**

All data and information developed or collected pursuant to the Parkinson's Disease Registry Act and the receipt and release of data from the Parkinson's Disease Registry is subject to and shall comply with sections 81-663 to 81-675. For purposes of the Parkinson's Disease Registry, data may be released as Class I data, Class II data, Class III data, or Class IV data as classified in section 81-667.

**Source:**

Laws 2001, LB 152, § 12.

**81-6,105**

**Patient and patient's family; privacy rights.**

Nothing in the Parkinson's Disease Registry Act shall be deemed to compel any individual to submit to any medical examination or supervision by the department, any of its authorized representatives, or an approved researcher. No person who seeks information or obtains registry data pursuant to the act shall contact a patient on the registry or such patient's family unless the registry has first obtained the permission of such patient or patient's family. The registry shall coordinate its activities with the person desiring such contact and may authorize the person desiring such contact to perform these contacts under the direction of the registry.

**Source:**

Laws 2001, LB 152, § 13; Laws 2002, LB 1021, § 108.

**81-6,106**

**Refusal to provide information; effect.**

Nothing in the Parkinson's Disease Registry Act requires a physician or pharmacist to deny medical treatment or services to an individual who refuses to provide the information necessary to make complete reports required under section 81-6,102 or 81-6,103.

**Source:**

Laws 2001, LB 152, § 14.

**81-6,107**

**Immunity from liability.**

Any physician or pharmacist required to make reports under section 81-6,102 or 81-6,103 is immune from liability, civil, criminal, or otherwise, for filing an incomplete report as a result of the failure of an individual to provide the information necessary to make such report.

**Source:**

Laws 2001, LB 152, § 15; Laws 2003, LB 667, § 23.

**81-6,108**

**Repealed. Laws 2003, LB 667, s. 26.**

**81-6,109****Transition from prior law.**

(1) On and after May 26, 2001, for purposes of the Parkinson's Disease Registry Act:

(a) Any rules, regulations, and orders of the Department of Health and Human Services Regulation and Licensure adopted pursuant to the former Parkinson's Disease Registry Act, as such act existed prior to February 14, 2001, and in effect on February 13, 2001, shall be revived and continue in effect until revised, amended, repealed, or nullified pursuant to law;

(b) Any contracts entered into by the department prior to February 14, 2001, and in effect on February 13, 2001, in connection with the duties and functions of the former act are recognized and may be revived upon the agreement of all contract parties. If revived, the department shall succeed to all rights and obligations under such contracts;

(c) Any cash funds, custodial funds, gifts, trusts, grants, and appropriations of funds which were available for use by the department for purposes of the former act shall continue to be available for use by the department if such funds continue to exist; and

(d) Any documents created, information compiled, or property used by the department under the former act shall continue to be available to and may be used by the department.

(2) For purposes of this section, former act means the Parkinson's Disease Registry Act, as such act existed prior to February 14, 2001, which act was outright repealed in Laws 2001, LB 209.

**Source:**

Laws 2001, LB 152, § 17.

**81-6,110****Costs; how paid; termination of registry; when.**

Costs associated with administration of the Parkinson's Disease Registry Act shall be paid from cash funds, contract receipts, gifts, and grants. No general funds shall be used to pay such costs. Funds received by the department for the payment of such costs shall be remitted to the State Treasurer for credit to the Department of Health and Human Services Regulation and Licensure Cash Fund. Notwithstanding any other provision of the act, the Parkinson's Disease Registry and all duties related to the administration of such registry and such act shall cease as of June 30 of any year in which the department has insufficient funds on hand to perform its duties under the act for the next fiscal year, after providing thirty days' written notice to each approved researcher who has contracted with the department under section 81-6,101 in the current biennium.

**Source:**

Laws 2001, LB 152, § 18; Laws 2003, LB 667, § 24.